Instructions for Completion of Client Data Entry for the Family Caregiver Support Program

Please retain only latest copy

REVISIONS:
Revised 3-23-04; 7-6-04; Effective 7-1-04; revised 11/04

This version incorporates changes as prescribed by the National Aging Program Information System (NAPIS) effective 7-1-04 for Title III E. This includes a requirement to count all leveraged resources. There is an option in the Caregiver Database to list all leveraged resources by service category and date.

Service categories are defined to be in line with the National Aging Program Information System (NAPIS) service definitions. Please review them carefully.
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Introduction
The Older Americans Act (reauthorization 2000)[1] provides the legislation creating the National Family Caregiver Support program. The North Carolina Division of Aging and Adult Services has provided Area Agencies on Aging the Family Caregiver Support Program (FCSP) Database to collect data on services provided to family caregivers by this funding[2]. Reporting of client demographics and service utilization demonstrates that your program and the state are reaching the intended audience and that the funds are being used for appropriate services.

The following is taken from the U.S. Administration on Aging's State Program Report document (NAPIS report):

> Overview of Title III and VII State Performance Reporting Requirements
> In the 2000 reauthorization of the Older Americans Act, the Administration on Aging (AoA) was instructed to use, to the maximum extent possible, the data collected by State agencies, area agencies on aging, and service providers through the National Aging Program Information System (NAPIS) and other applicable sources of information in the development of performance measures, and in compliance with the Government Performance and Results Act of 1993.
> The Assistant Secretary for Aging was also instructed to annually report to the President and to the Congress on the activities carried out under the Older Americans Act. This report includes (section 207 (3)) *statistical data and an analysis of information regarding the effectiveness of the State agency and area agencies on aging in targeting services to older individuals with greatest economic need and older individuals with greatest social need, with particular attention to low-income minority individuals, older individuals residing in rural areas, low-income individuals, and frail individuals (including individuals with any physical or mental functional impairments).*
> As a response to these mandates, AoA is issuing revised reporting guidelines for Titles III and VII. These OMB approved reporting requirements are a revision of those which are currently in effect. The factors which influenced the revision of the SPR, include: 1) the need to develop more permanent information requirements for the National Family Caregiver Support Program (NFCSP); 2) the need to comply with revised OMB standards for gathering information regarding race and ethnicity; 3) the need to reduce the burden of the SPR/NAPIS requirements on States, area agencies and service providers; and 4) the need to consider the collection of alternative data elements to reflect Network performance.

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[1] Older Americans Act, Title III, November 13, 2000 amendments.
[2] Services provided through other funding sources should not be reported through the FCSP Data Base.

Time Line
The FCSP Database was released to the aging network originally in the fall of 2002 and was utilized for data collection for services provided beginning July 1, 2002. It is understood that family caregivers may receive services that span more than one fiscal year. Therefore, data collected during each program year will remain within the database for a number of years.

When you see a blue question mark (?) it indicates that further information on that entry field is available by clicking on the question mark.

Entering Client Data

Signatures: Signatures of caregivers served are required on the intake form which includes a statement of confidentiality.

Category I Services

Fig. 1. Step 1 in adding Category I services.

Fig. 2   Step 2 in adding Category I services

Category I services (information services) are entered into the Category I input form. This category consists of "group activities" and public communications rather than one-on-one caregiver contact. "Information services" include a service for caregivers that provides the public and individuals with information on resources and services available to the individuals conducting media campaigns, and other similar activities.
(Examples of Category I services: community and program relations, advocacy, outreach, assessment, planning and oversight for Cat. I services; T.V, newspaper, and radio ads, resource fairs, brochure distribution, public service announcements and stories; publication distribution and other as approved by the Division of Aging and Adult Services.)
Caregiver workshops which include registrations, FCSP dollars expended on food, materials, location, and other items necessary to conduct a workshop would be reported under Category III.

> **NOTE:** **Community and program relations, advocacy, outreach, assessment, planning and oversight have all been counted *previously* in Category I to encompass the implementation of the program. The Administration on Aging requires that we count activities toward development and oversight into the *relevant* category. *(This is a change in NC's directive on this subject.)* For example, if you are working to develop a Support Team to provide respite dollars should be shown in Category IV on the FCSP Exhibit 5 where previously it would have been counted in Category I). There is an activity for Program Planning, Coordination, Assessment, Resource Development and Oversight listed for every category.**
> **For further information on where to count your time for your salary, please check with your finance officer within your agency.**
> ***The above activities, if for outreach advocacy for the FCSP in general, it would continue to be placed into Category I.***

Box 1

Category I services are registered as a "count" only. One event equals one unit. We are also required to estimate the audience size. We do not collect demographic data on the caregivers receiving these services.

Fig.1

1. Date: Current date entered automatically by computer.

2. County: Choose region or county from drop down menu.

3. Type of Activity: Face-to-face (resource fairs; presentations to large groups on the caregiver program) and; **media** (radio and TV ads and discussions; newspaper ads and articles; website initiatives). If two activities occur within the same county on same date, it is permissible to change one to the next day for data entry.

One activity equals one unit. Service units are for activities directed to large audiences of current or potential caregivers such as disseminating publications, conducting media campaigns, and other similar activities. One service unit equals one activity. We will count the units based on number of entries.

Fig. 2
4. Description: Use this text box to give significant facts or interesting details about the event.

5.   Total Participants or Estimated Audience
Count or estimate participants to the best of your ability. This will capture caregivers and "potential" caregivers. Count newspaper circulation, all attendees at a resource fair, listening audience for radio and viewing audience for T.V.
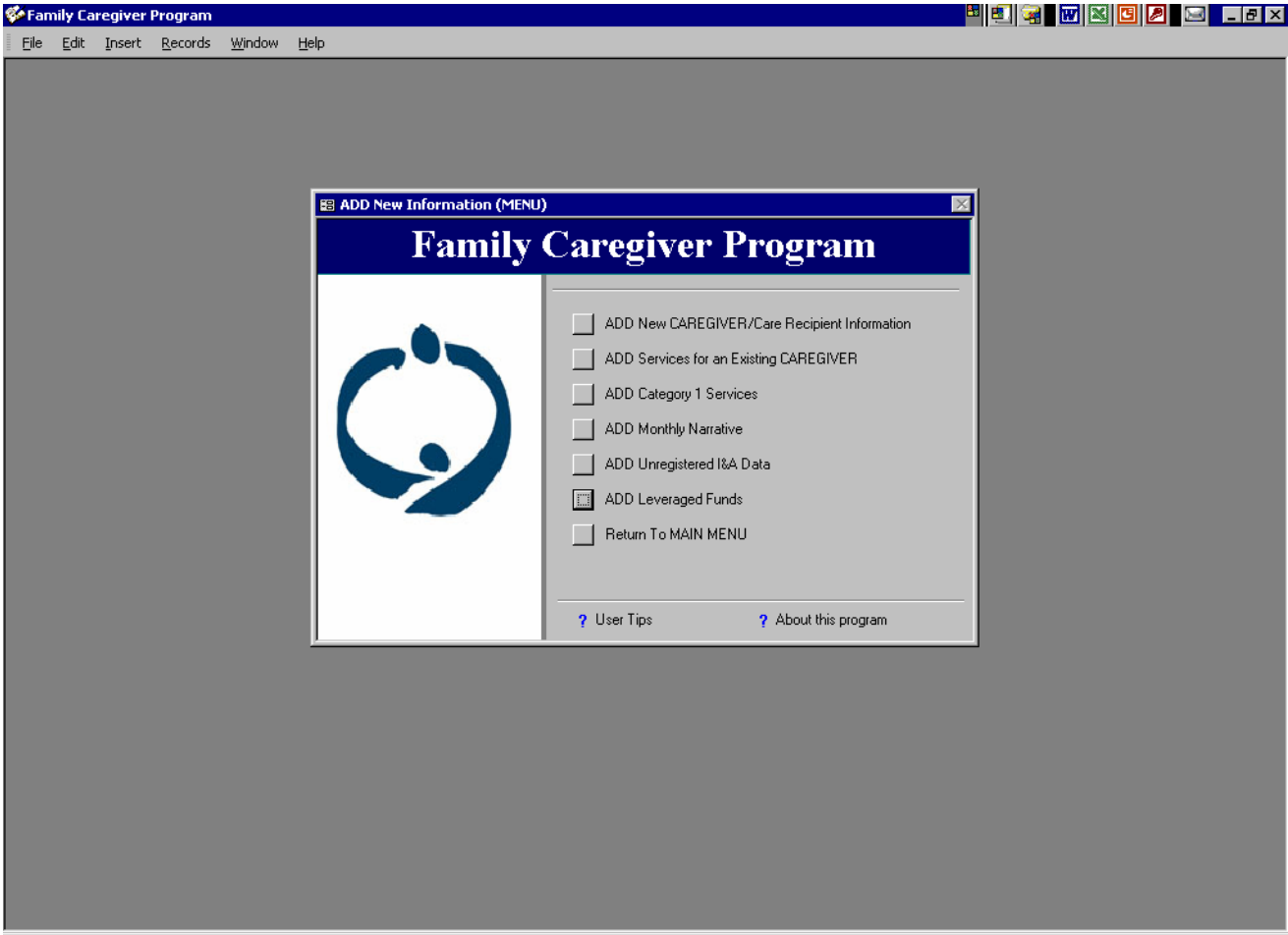
Fig 3

Fig. 4

6.   Leveraged Resources

The AAA doesn't have to fund an event in order to count it for Category I. If the AAA is instrumental in making an event happen and leverages support from other community providers, the attendance/audience as well as leveraged resources can be counted. Examples of leveraged resources:

- ♦ Facility cost (if another source donates or pays for use of facility)
- ♦ Speaker cost donated or paid for by another source
- ♦ Advertising for event given free or paid for by another source
- ♦ Refreshments and entertainment
- ♦ Donation of time and skills

Click the "Add Leveraged Funds" as seen in **Fig. 3** above.   Click and enter information as seen in **Fig. 4**. Add a description or reference the event already described (as in Fig. 2). Include a brief narrative on how/what was leveraged. Enter approximate dollars leveraged in the box provided.

Category II-V Services

All caregivers receiving services in Categories II-V must be registered in the FCSP database in the intake form as seen below. The only exception is for clients in Category II receiving the "information" part of I&A. The count may be entered monthly by county and the total will appear on your Statistical Summary Report.

Fig. 5 (corresponds with intake form). There is adequate space in the database to enter three care recipients.

Intake Form
The intake form can be printed by "Go to Report Menu" (on main menu page) and then clicking on "Other Report options" (Menu) and then clicking on "Blank Intake Form".

Caregiver (client) Information
It is crucial that information provided is complete and accurate so that program assessment and local, state and federal program surveys can be conducted.

7. Intake Date: The computer automatically generates this.

8. SSN or ID Number: To enter the intake form area where new clients for Categories II-V are entered, you must enter a Social Security Number or another identifying number.
- If client does not wish to give SSN, please use the established procedures found on the Division of Aging and Adult Services website to assign an identifying number.
- The database will have a link to this website. Click on the **?** beside the word SSN or ID to go to the website below.
- http://www.dhhs.state.nc.us/aging/arms/ssnassgn.htm

9. Telephone number of the caregiver
- Including area code

10. Last Name, First Name
- Type first and last name in appropriate boxes.

11. Mailing Address
- It is important to distinguish this from the residence (physical) address, if they are different. The AAA, the state, the AOA may need to send out follow up surveys or information to the mailing address.
- County (where service is provided)

12. Gender
Self-explanatory

13. Health of the Caregiver
Self described by the caregiver as well, fair, or poor

14. Urban or Rural
- Client is self-described as urban or rural.

15. Long Distance Caregiver (yes/no)
Does caregiver live more than one hour away from care recipient.

16. Does the caregiver work?
If yes, answer full or part-time. Or answer "no".

17. Birth date:
- Enter birth date. If client provides only age, enter January 1 of the correct year.

18. At or Below Poverty Level?
- Income is self-declared for caregiver's family. Based on Federal Poverty Level for family size found at http://aspe.hhs.gov/poverty/04poverty.shtml

19. Ethnicity/Race
- Choices have changed from previous database and will be in two categories: ethnicity and race.
- You will be asked to choose **Race:**
    - White
    - Black or African American
    - Asian
    - American Indian/Alaska Native
    - Native Hawaiian or Other Pacific Islander
    - Some other race
    - Two or more races

    AND;
- **Ethnicity (yes or no answer)**
    - Hispanic or Latino

Information about the care recipient(s)

20. Full name: Last name and first name last in appropriate boxes.

21. Birth date: Enter birth date. If client provides only age, enter January 1 of the correct year.

22. Relationship to Caregiver
- Care recipient is spouse, parent/parent-in-law, grandparent, other relative, or other non-relative.   There is also a choice to include grandchildren or other relative 18 and under.

22. ADLs: Based on self-report, caregiver report, or professional assessment
- **Eating:** Can care recipient feed herself/himself independently?
- Is assistance with **bathing** needed?
- Is assistance in getting **dressed** needed?
- **Toileting:** Can care recipients manage their own toileting needs (getting to the bathroom on time; ability to manage dressing and undressing for this purpose; is personal hygiene appropriate related to toileting)?   A person who is incontinent but can manage changing their own incontinence supplies appropriately would be considered independent in toileting.
- **Incontinence**: Is care recipient incontinent of bowel or bladder?
- **Transfers:** Can care recipient get in and out of bed and chairs unassisted?
- **Ambulation**: Can person walk without human assistance, even if they use an assistive device (walker, cane, wheelchair)?
- **Communication**: Does care recipient have the ability to express needs to others, even if it is non-verbal? This includes use of speech, written word, signing, gestures, and communication devices.

23. Lives with Caregiver:

- Are caregiver and care recipient **living at same address?** This can be in the official residence of either caregiver or care recipient.

24. At or below poverty level

- For **care recipients** and spouse (or if other dependents)
http://aspe.hhs.gov/poverty/04poverty.shtml

25. Cognitively Impaired: Check "yes" if care recipient is cognitively impaired.

The caregiver, service provider after assessment, or other qualified professional can state that they believe care recipient is cognitively impaired.
[In Block Grant reporting, the form reads "Is client oriented" which is an opposite response to the FCSP intake form. The block grant definition, however states that a client has had a significant decline in short-term memory, thinking or decision making (however, client may still be oriented to person, place or time.)]

Fig. 6 (Screen for registered clients receiving serves in Categories II-V.

Fig. 7 Intake Sheet page to add services for client.

25. Category II: Assistance with Access
Access Assistance is a service that assists caregivers in obtaining access to the services and resources available within their communities. To the maximum extent practicable, it ensures that individuals receive the services needed by establishing adequate follow-up procedure.

One contact is counted as one unit for data reporting. Internet website "hits" are to be counted only if information is requested and supplied. Otherwise website "hits" would be included under Category I. Providers who give assistance over the phone are encouraged to register callers who receive assistance and follow-up as a part of Category II Assistance with Access to Services, although this is not mandatory. Registering clients will help in follow-up and in the event the caregiver calls again. All calls are counted by contacts under I&A/ hotline calls in the database.

Register clients for all services except unregistered I & A after completing page 1 of the intake form. You must then click on "Add Services for an Existing Caregiver" to add them. This is page 2 of the printed intake form. See **Fig. 7** above.

Category II services include:

- Information & Assistance (I&A), telephone helpline or hotline. (enter in the Hotline/I&A screen)
- Care management
- Care planning
- Develop caregiver emergency plan (e.g., hospitalization plan, back-up respite service, and enrollment on special needs registry)
- In-home caregiver assessment
- Benefits screening/assessment
- Program Planning, Coordination, Assessment, Resource Development and Oversight (this will not be included on the client intake form, but on database only)
- Other as approved by DOA

Fig. 8 Information and Assistance and Telephone Hotline (Step 1)

Fig. 9 Adding the number of unregistered I & A clients. (Step 2)

When should caregiver calls be counted as I&A and when should they be counted under the FCSP for Category II?

♦ Agency is funded by HCCBG for I&A **and** Title III-E I&A. Agency may count initial calls as I&A contact and when referred to Caregiver Program for further information or assistance, all contacts with the caregiver would be counted as FCSP contacts for Category II, Title III-E I&A.

♦ Note: Although the functions are identical for Title III I&A and Title III-E I&A, data collection will focus on the older adult and caregiver respectively.

♦ Both Title III and Title III-E are umbrella programs for additional services.

Leveraged Resources

Count all leveraged resources such as donation of a computer system for I & A; volunteers collecting data for I & A; volunteers providing I&A or care management; persons providing these services for reduced cost (count the difference in cost vs. market value). Care management and other volunteer hours for specific services would be based on the nationally recognized dollar amount established for volunteer time. *(Please see box below.)* Count the value of an hour of their time (e.g.; if a care management agency donates 8 hours of service to family, count 8 units and count the cost/value of leveraged funds as the cost.) Click the "Add Leveraged Funds" as seen in **Fig. 3** above.   Click and enter information as

seen in **Fig. 4**. Add a description or reference the event already described (as in Fig. 2). Include a brief narrative on how/what was leveraged. Enter approximate dollars leveraged in the box provided.

Putting a Dollar Amount on Volunteer Time: The national dollar value of volunteer time is released each year by the non-profit Independent Sector (IS). IS calculates the figure by using the average hourly earnings of all production and non-supervisory workers on private non-farm payrolls (as released by the Bureau of Labor Statistics) and increasing it by 12% to account for fringe benefits. This agency's figures are used and accepted nationally.

This represents an average value of volunteer roles and activities. It ranges from basic, simple tasks that might be valued at minimum wage, up to professional services given by doctors, nurses, lawyers, accountants, social workers, etc. that would be have a higher dollar value.

The estimated dollar value of volunteer time is $17.19 (2003 figures effective for use March 04-February 05)

This changes annually, so please check the website for IS at http://www.independentsector.org/.

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26.   Category III: Counseling, support groups and caregiver training.

Services to caregivers to assist them in making decisions and solving problems relating to their caregiver roles. This includes counseling to individuals, support groups, and caregiver training (of individual caregivers and families).   One session equals one unit.   Some examples include:

- Caregiver counseling (caregiver issues, financial, end of life, grief, and peer)
- Support groups (caregiver, widow, peer, grief)
- Workplace caregiver support (support groups and training)
- Legal counseling
- Caregiver training programs
- Program Planning, Coordination, Assessment, Resource Development and Oversight
     (This is not on the client intake form, but in the database only)
- Other as approved by DOA

Leveraged Resources
The AAA doesn't have to fund an event in order to count it for Category III. If the AAA is instrumental in making an event happen and leverages support from other community providers, the attendance/audience as well as leveraged resources can be counted. Examples of leveraged resources:

- Facility cost (if another source donates or pays for use of facility)
- Speaker cost donated or paid for by another source
- Advertising for event given free or paid for by another source
- Workshop materials
- Refreshments and entertainment
- Donation of time and skills

♦ Pro-bono legal, counseling or other

Click the "Add Leveraged Funds" as seen in **Fig. 3** above.   Click and enter information as seen in **Fig. 4**. Add a description or reference the event already described (as in Fig. 2). Include a brief narrative on how/what was leveraged. Enter approximate dollars leveraged in the box provided.

27.   Category IV: Respite Care

Services which offer temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for caregivers. Respite Care includes:

♦ In-home respite (personal care, homemaker, and other in-home respite including care provided by Senior Companions/home visitors.)
♦ Respite provided by attendance of the care recipient at an adult day center, respite center, mobile day respite, or other nonresidential program.
♦ Emergency respite program
♦ Institutional respite provided by placing the care recipient in an institutional setting such as a nursing home or assisted living for a short period of time to provide respite to the caregiver; and
♦ Summer camps, after-school programs or child day-care (for grandparents caring for grandchildren)
♦ Other short-term respite options (e.g., respite camps and caregiver retreats)
♦ Other as approved by DOA

And respite services for reporting in database include:
♦ Program Planning, Coordination, Assessment, Resource Development and Oversight
(This is not on the client intake form, but in the database only)

Data entry information:
- Service units:
    - Institutional and congregate respite hours (adult day care; group respite; and institutional respite) list *# of whole days* of service.
    - Other respite service (in-home) units are listed by *WHOLE HOURS*!
- **The database will not accept decimals!**
- Rounding hours:
    - Providers should total clients' monthly hours (if aide service, other). If aides or other workers are paid by half-hour or quarter-hour, alternate rounding clients up and down by the following formula.
    - Total each client's hours by the month. Round .25 down and round .75 up. All .5 hours should be alternated rounding up for first client and then down for the second.

Leveraged Resources

Sub-contracting with a provider for respite service to clients for a specified dollar amount would *not* be considered leveraging resources. Units of service would simply be reported, caregivers would be registered and the cost of providing the units would be included in the contract and reimbursed through ARMs.

Examples of *leveraged* resources *would* include:
- ♦ volunteer respite hours provided
    - ♦ Suppose the AAA funds staff to recruit, train and coordinate volunteer respite providers.
    - ♦ We would register the clients served by the volunteers
    - ♦ We would track the volunteer hours to count as dollars leveraged.
- ♦ If the Family Caregiver Support Program involvement made respite possible by
    - ♦ applying for and receiving a grant;
    - ♦ pulling in other organizations to donate staff or coordinate volunteers who provide respite;
    - ♦ and/or being instrumental in bringing support teams or other similar efforts into the region, we need to report all donated hours and place a dollar amount on those hours. Click the "Leveraged Resources" box and enter approximate dollars leveraged.

Click the "Add Leveraged Funds" as seen in **Fig. 3** above. Click and enter information as seen in **Fig. 4**. Add a description or reference the event already described (as in Fig. 2). Include a brief narrative on how/what was leveraged. Enter approximate dollars leveraged in the box provided.

28. Category V: Supplemental Services
These are services provided on a limited basis to complement the care provided by caregivers. This is a one-time service and should not be ongoing.
Examples of supplemental services include:
- Home safety interventions/evaluations
- Access to assistive technology
- Handy man, yard work, or household chore work (i.e., house cleaning for caregivers)
- Equipment loans
- Home modifications (e.g., lift chairs; grab bars, assistive devices, ramps, etc.)
- Personal emergency alarm response systems
- Incontinence or other caregiving supplies
- Telephone reassurance
- Liquid nutritional supplements (e.g., Ensure or Boost)
- Home delivered meals (temporary)
- Transportation (medical or other)
- Other as approved by DOA
- Program Planning, Coordination, Assessment, Resource Development and Oversight (This is not on the client intake form, but in the database only)

Units are counted as below:
- For nutritional supplements, two cans equal one unit.
- Home delivered meals would be 1 unit per delivery.
- Medical transportation is one unit per one-way trip.
- Other one-time efforts would be 1 unit.

Leveraged Resources
Count resources leveraged where AAA or local provider through FCSP was instrumental in developing the resource.
Examples:
- You have talked to a church or other group and because of your encouragement; they have decided to build ramps. The FCSP pays for the supplies. You would count the volunteer hours as leveraged resources
- With a donation of incontinence supplies, transportation, durable medical equipment, etc. count the market cost of the item as a leveraged resource.

Click the "Leveraged Resources" box and enter approximate dollars leveraged.
Include a brief narrative on how/what was leveraged.

Fig. 10

Other narrative information or new initiatives can be reported in the Narrative text box. Be sure to include region and date.

Questions and Answers: (Q & A)

WE WILL ADD TO THESE AND SEND THEM OUT AS WE RECEIVE THEM

Q 1: If a provider does not have the information about the care recipient, can they enter the information? Could they list the caregiver as Jane Doe?
A: *Those people should not be entered into the database. Furthermore, the provider should not receive reimbursement for services provided to people for whom they do not have accurate information. They should hold off entering this data until all information can be obtained. We do not want our data collection to be skewed because of guesses about who is receiving assistance.*

Q 2. The experience with Category 1 is that only ONE event can be entered per date, is this correct? If so, are there any suggestions about how to work with multiple events on the same date?
A*: For multiple Category 1 events - only one type per county/region per date can be entered. Therefore 3 different events can be entered for the same county for a particular date; they just have to be different types (face-to-face, media, and other). If you had more than one of the same type of event or activity on the same date within the same county, it is permissible to change one to the next day for data entry purposes.*

Q 3. Some providers enter Category 1 information under the Region name rather than the county. How can I change these entries to reflect the correct county?
A: *Category 1 corrections - If the wrong County/Region was entered you must delete the record and enter it in again using the correct County/Region. This is a unique identifier and therefore cannot be modified after it has been entered.*

Q 4: An out of state caregiver used the FCSP service but we don't have an "out of state" choice, just the 100 NC counties.
A: *If he/she received I&A, there is no registration required. Perhaps the caregiver received respite in NC in order for the caregiver to stay home for a weekend rather than to come to NC to provide care for a family member. If the care recipient is in NC, then register with the care recipient's location because the care and the role of caregiving are occurring in North Carolina.*

Other:
Grants and Leveraging Funds/Services

- The grant status report is an on-going status report regarding any additional leveraging of funds that have been applied for or have been received by the AAA. Dollar amount should be placed in appropriate service category.
- Funds which have been applied for by partnering* agencies which will assist caregivers should be described in this section.

(*this applies only if the Title III-E program is a contributing partner).